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Original Article

Factors associated with self-perceived state of health in adolescents with congenital cardiac disease attending paediatric cardiology clinics

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Abstract The purpose of our study was to determine the ways in which adolescents with congenital cardiac disease believed that the condition had affected their life, and how these views were related to their perceived health. Interviews were conducted with a series of 37 adolescents, 17 girls and 20 boys, aged from 11 to 18, as they attended the clinics of 4 paediatric cardiologists in a teaching hospital in the United Kingdom. Transcripts of the interviews were analysed for recurring themes. A questionnaire was formed consisting of a set of questions for each theme, and additional items eliciting “perceived health”, and administered to a second series of 74 adolescents, 40 boys and 34 girls, who were again aged from 11 to 18 years. Slightly less than half (46%) perceived their health as either “good” or “very good”, and one-third (33%) rated it as “average”. The majority (66%) felt themselves to be “the same” as, or only very slightly “different” from, their peers. The assessment of the seriousness of their condition by the adolescents, the degree to which they saw themselves as different from others, and their perceived health, were not related to the “complexity of the underlying medical condition” as rated by their physician. It was the psychosocial themes, such as exclusion from activities or the effect of the condition on relationships, that were most strongly related to the perception of their health by the adolescents. Improved education of parents, teachers and peers, and attendance at classes for cardiac rehabilitation, might help to ameliorate some of these problems.

Keywords: Congenital heart disease; perceived health; rehabilitation; psychological factors

STUDIES OF PSYCHOSOCIAL FUNCTIONING IN adolescents and young adults with congenital cardiac disease have produced varied results. Some have reported favourably on quality of life, finding few problems of adjustment and little in the way of health-related deficits in quality of life.^{1–3} These studies have predominantly measured physiological parameters, such as performance on the

treadmill and reports of symptoms. Not surprisingly, there is often a wide variation between the maximal functional ability of those with very minor defects and those with complex problems, such as the functionally univentricular heart.⁴ Others, usually the more psychologically orientated studies, have reported an increased risk of poor psychosocial outcome. Problems reported have included low self-esteem, high levels of anxiety and depression, and poor social and behavioural adjustment.^{5–9} Many of these studies have used instruments designed to examine psychopathology or developmental difficulties in “normal” children and adolescents. There have been very few open-ended studies of the perceptions of their health by adolescents with congenital cardiac disease. Tong et al.¹⁰ used interviews to

Correspondence to: Professor R. J. P. Lewin, British Heart Foundation Rehabilitation, Research Unit, Genesis 6, York Science Park, University of York, Heslington YO10 5DG, UK. Tel: 01904 434127/434106; Fax: 01904 434102; E-mail: rjpl1@york.ac.uk

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examine the dilemmas reported by adolescents and young adults with congenital cardiac disease. They found seven recurring themes, normality, disclosure, strategies for management of the illness, integration versus isolation, dependency versus independence, the challenge of uncertainty, and strategies for coping.

Findings have often proved contradictory. For example, one of the largest studies, incorporating 288 patients interviewed from 9 to 23 years after their surgery,¹¹ reported that, compared to a reference group, young adults with surgically corrected deficits scored favourably in terms of hostility, neurotic complaints, and self-esteem. In this study, no differences were found between the different diagnostic groups. From the naive lay viewpoint, this may appear surprising. It is generally assumed that the "worse" the illness, the more distressed and disabled will be the patient. Every clinician receives regular reminders that this is not true, particularly in adults with chronic illnesses, where there is rarely any consistent relationship between the extent or degree of the underlying physiological impairment and the extent of the symptoms or distress demonstrated by the patient.

For some time, psychologists working in the field of health have been trying to understand the factors that predict behaviour, such as smoking or return to work, and the state of health, such as reports of symptoms or disability, with a view to improving both. It has become clear that explanations of the generally poor association between impairment and disability will require a dynamic "model" that will include medical, psychological, and social factors. Numerous variables have been suggested as mediators between the physiological state and the behaviour of patients. For example, in a study in congenital cardiology, Bar-Mor and colleagues showed that "self-efficacy", in other words a belief in one's ability to achieve goals, mediated by advice from the cardiologist and mother, were related to the levels of activity achieved by adolescents with trivial, mild or moderate cardiac malformations. The level of impairment, however, showed no significant relationship to the levels of activity.¹²

In most psychobiological models of health behaviour, it is implicit that it is the perception of the patients, and not (necessarily) the objective truth, that is important. A perception that has been shown to be related to aspects of coping with chronic illness in adults with acquired cardiac disease is "perceived health".¹³ This term describes the way in which patients view their overall health compared to others. This is also sometimes called "global health", and has been shown to be a predictor of outcome after myocardial infarction. In a three-year study conducted in Scandinavia, 200 patients suffering

myocardial infarction were followed from 3 days after their heart attack for two years. Patients who continued to rate their global health as low were less likely to return to work, more likely to be readmitted to hospital, and more likely to become cardiac invalids. It might be suggested that this was because they were more ill. Once again, however, the perception of health by the patient did not correlate with any objective measures of cardiac disease.^{14,15} We are not aware of any other study that has examined the perceived health of adolescents with congenital cardiac disease. We consider it important not to assume communality between the beliefs of adults with acquired cardiac disease and adolescents who have never known any other state than a cardiac condition. The work reported here, therefore, is an atheoretical observational study in the form of a survey of beliefs and attitudes conducted using a questionnaire.

Methods

The study comprised two parts. The first involved semi-structured face-to-face interviews about living with the condition, and was designed to elicit common "themes" that would form the "domains" of a questionnaire that could be administered to a larger sample. Ethical approval was obtained from the Hospital's Ethics Committee, and informed consent was obtained from all of the respondents and their parents.

Part 1: Interviews and formation of the questionnaire

A convenience sample of consecutive attendees, 17 girls and 20 boys, between the ages of 11 and 18, with a mean of 14.95 years \pm 2.03, who attended our paediatric cardiologic outpatient clinic between December 1998 and February 1999, were interviewed to "help us better understand the problems of our patients". The sample included patients with a broad range of conditions (shown in Table 1). The only exclusion criteria were being unable to speak English, or having a significant neurological impairment noted in the case records.

The semi-structured interviews were conducted by one of three members of the research team (LK, GV, JQ). They took place in a quiet room in the absence of the parent/s, and lasted for between 20 and 30 minutes per patient. Interviews were audio-taped and transcribed. Conversation was stimulated by a series of open-ended questions.¹⁶ A guide to topics was developed based on the previous literature of problems reported by patients and healthcare staff and our own clinical experience. Questions were open-ended. They were designed to explore

Table 1. Summary of the main diagnoses of the 37 interviewed patients.

Main diagnosis	Number of Patients
Complete transposition (Senning/Mustard)	5
Tetralogy of Fallot	5
Fontan circulation/functionally univentricular heart	8
Aortic Stenosis	6
Ventricular & atrial septal defects	3
Supraventricular tachycardia	2
Others*	8

N = 37. *The group called "others" contains diagnoses of atrioventricular septal defect, totally anomalous pulmonary venous connection, mitral valvar replacement, right ventricular outflow tract obstruction, Marfan's syndrome, double outlet right ventricle, pulmonary stenosis, and hypertrophic cardiomyopathy

family relationships, friendships, school, physical and sporting activity, recreation, worries about having a cardiac problem, expectations for the future, and their understanding of their condition. Three of the researchers (GV, LK, JQ) analysed the transcripts using the "framework approach".¹⁷ This involves familiarisation with the data, followed by indexing of data into a thematic framework. This data is then gathered onto a series of charts, one for each theme. Finally, the key characteristics of the data are pulled together, enabling mapping and interpretation of the whole data set. The themes emerging from the interviews were agreed by the research team, and any differences in interpretation were resolved by discussion. The researchers then developed a set of questions for each theme (or domain), using typical remarks taken from the transcripts.

In addition to the questions generated as described above, we added a scale to gather the frequency of symptoms. The patient was asked how often he or she experienced being short of breath, having palpitations, feeling cold and going blue on a set of five point scale from "never" (1) to "all of the time" (5). Three items regarding the general view of their health were then added. Two were visual analogue scales rated from 1 to 10 (with 1 representing least and ten most) in answer to the questions, "how serious do you think your condition is?" and "how different do you feel from other people your age?" The third item, measuring perceived global health, was a five point scale, where 1 represented "very good" and 5 "very poor", in answer to the question "how would you describe your general health?".

Part 2: The response to the questionnaire

The questionnaire was administered to a second series of 74 adolescents, 40 boys and 34 girls, aged between 11 and 18 years, with a mean of

14.03 years \pm 1.98, when they attended for their appointments at the outpatient clinic. They completed the questionnaire without help from their parent/s in a quiet environment away from the ward.

In addition to the questionnaire, we created a "grading of condition" by the physician for each respondent. The system was arrived at following discussion with the multi-disciplinary clinical team. It is our opinion that the grades reflect clinically recognisable groupings. Scores ranged from 1–5 using the following pre-ordained guide:

- 1 The condition is self-limiting and patients can usually be discharged with no follow-up and normal life expectancy, for example, those with a small ventricular septal defect.
- 2 Patients in this group will have undergone successful surgery or intervention and no further intervention is anticipated, for example, repair of an atrial septal defect.
- 3 Patients with disturbances of rhythm where future intervention is possible or probable, for example, change of pacemaker.
- 4 Patients with more complex defects, many of whom will require further interventions or surgery, for example, those with complete transposition or tetralogy of Fallot.
- 5 Patients in whom a reduced life span is expected despite therapeutic interventions, as for example those with functionally univentricular heart.

Patients were allocated to these groups by the consultant paediatric cardiologists and the research team from information recorded in clinical case notes.

Statistical methods

An index was created for each domain in the questionnaire. Where the domain could usefully be separated into separate sub-domains, this was done. For example, the theme "limits on activity" was split into 3 separate indexes representing three different kinds of restriction:

- a limitation of self-directed hobbies or play,
- a limitation of competitive or organised sports undertaken voluntarily, and
- a limitation of the normally compulsory school physical education classes.

The 8 domains were sub-divided as described above to form the following 11 indexes:

- *Physical symptoms* – the frequency of 4 common physical symptoms, breathlessness, palpitations, feel cold, going blue.

- *Physical limitations (a)* – physical limitations of self directed activities, such as playing, running, walking, bathing, hobbies.
- *Physical limitations (b)* – limitations in voluntary sporting activities, summed with the limitations in (a).
- *Limitation of physical education at school.*
- *Social limitations* – limitations in social activity such as going out, having fun with friends, and so on.
- *External pressures* – pressures from others such as peers, parents, teachers, doctors.
- *General concerns* – a variety of concerns or worries such as having to take medication, visit hospital, and so on.
- *Physical concerns* – concerns or worries about the safety of physical activity.
- *Social concerns* – concerns or worries about social activity and friendships.
- *Educational concerns* – concerns about the effect of the condition on prospects for education and work.
- *Total concern* – the sum of the last indexes relating to “concerns” to create a combined score.

Scores for each item were summed to provide crude scores for each of the indexes. Non-parametric procedures, namely the Mann-Whitney test; the Kruskal-Wallis test; or Spearman's rank correlation, were employed to investigate relationships between the indexes and the various self-reported health and psychosocial items. All quantitative analysis was undertaken using the statistical computer software SPSS.¹⁸

Results

Part 1: Interviews and formation of the questionnaire

We approached 41 children, of whom 40 (98%) agreed to take part and were interviewed. Three interviews were inaudible due to poor recordings, leaving 37 interviews for analysis. Eight themes were identified and agreed by the researchers. These were physical activity, symptoms, anxieties, family relationships, friendships, education/school, identity and understanding of the illness, and medication. Items were generated for each, and the final questionnaire comprised 50 questions, including the symptom scale and the 3 questions concerning the self-perceived state of health.

Part 2: The response to the questionnaire

A series of 74 children, 40 boys and 34 girls, agreed to take part and completed the questionnaire successfully. Some children aged 16 years old were

not at school and, for those aged 17 and 18 years, a number of the questions relating to school and compulsory sporting activity were not relevant. Analysis, therefore, was carried out only on 57 children aged between 11 to 16 years and at school. These comprised 31 (54.4%) boys and 26 (45.6%) girls, with a mean age of 13.2 years (standard deviation = 1.32) and a range from 11 to 15 years. The modal age was 14 years (28.1%). No items in the questionnaire were significantly related to age or gender, except that the older the child, the more likely they were to report that they knew enough about their condition (Spearman rank correlation coefficient 0.3219, $p < 0.01$).

Table 2 shows the range of diagnoses for the 57 patients who completed the questionnaire.

The scale rated by the physicians revealed that the majority of children had complex problems, 58% being classified at 4, and a further 14% at 5 (Fig. 1). The responses to the three questions concerning perceptions of health are presented in Figures 2 to 4.

There was no statistically significant relationship between the rating of the seriousness of the condition of the patients, their rating of their global health, their difference from others, or the grading of complexity made by the physicians.

The statistical significance of the relationships between the 11 domain indexes, the ratings of global health, difference from others, and seriousness of condition and the complexity of the condition as rated by the physicians are shown in Table 3.

The strength of the relationships between the 11 indexes and the ratings by the patients of global health, difference from others, seriousness of condition, and the complexity of the condition as rated by the physicians are shown in Table 4.

Limitations of the research

The limited number of cases, and the solitary center for recruitment, mean that the conclusions must be treated with some caution. Furthermore, the sample was drawn from those who attend clinics for paediatric cardiology, not the total population of adolescents with congenital cardiac disease. The patients, nonetheless, were a true series of those attending our multi-disciplinary clinics drawn from a population of 5.25 million people across a diverse geographical area, and there is no reason to believe that they were not similar to the patients seen in other centers for paediatric cardiology in the United Kingdom or elsewhere in the world.

The measure of severity that we devised from the stance of the physician may be criticised as non-standard. Inventing our own classification was

Table 2. Summary of the main diagnoses and severity of the lesion as rated by the physicians in the 57 patients who completed the questionnaire.

Main diagnosis	Number of patients	Physician rating of severity
Small ventricular septal defect (VSD) (1), Atrial Fibrillation (1)	2	1
Atrial septal defect (3), VSD (1), Pulmonary stenosis (2), Supraventricular tachycardia/ablation (1)	7	2
Congenital heart block/insertion pacemaker (3), supraventricular tachycardia (1), bradycardia (1), Palpitations with collapse (1)	6	3
Tetralogy of Fallot (10), Complete transposition (4), Aortic stenosis (6), Coarctation of aorta (4), Atrioventricular septal defect (1), Mitral valvar replacement (1), Aortic root replacement (1), Severe right ventricular outflow tract obstruction (1), Marfan's syndrome (3), Kawasaki syndrome (1), Sub-aortic stenosis (1)	33	4
Fontan circulation/functionally univentricular heart (5), Hypertrophic cardiomyopathy (2), Cardiac transplant (1)	8	5

N = 57 (diagnosis missing for one patient). Severity as rated by the physicians:-

1. The condition is self-limiting and patients can usually be discharged with no follow up and normal life expectancy.
2. Patients in this group will have undergone successful surgery or intervention and no further intervention is anticipated.
3. Patients with disturbances of rhythm where future intervention is possible or probable.
4. Patients with more complex defects, many will require further interventions or surgery.
5. Patients in whom a reduced life span is expected despite therapeutic interventions.

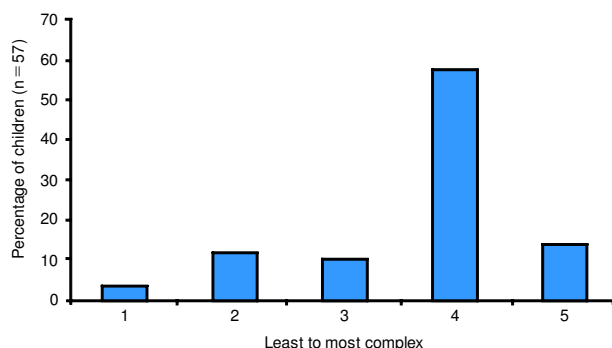


Figure 1.

The scale of grading by the physicians had a range from 1(least complex) to 5(most complex) and indicated that the majority of children had complex problems. 3.5%(2) were classified at 1, 12.3%(7) at 2, 10.5%(6) at 3, 57.9%(33) at 4 and 14%(8) at 5, one child was not categorised.

necessary because there is no universally agreed system for grading the severity of congenital cardiac malformations. The categories we chose were not intended to represent a measure of physiological impairment, rather they represent the “groupings of illness” as chosen by the physicians, and therefore the variety of prognoses given to the parents and child.

This was an observational study, not one designed to attribute causality or validate a particular hypothesis. We did not measure anxiety or depression, nor a number of other variables that might also be

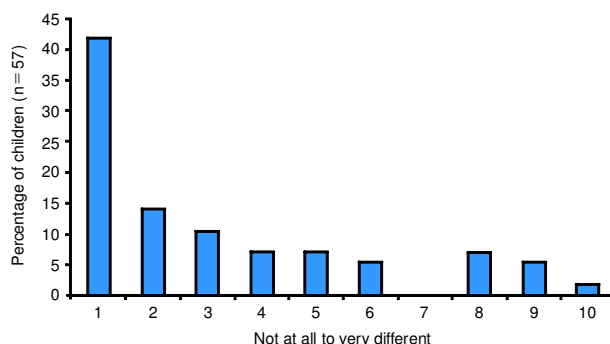


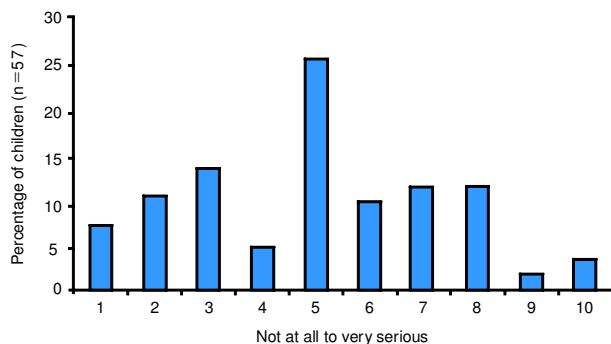
Figure 2.

The question, “how different do you feel from other people your age?” was presented on a 10 point visual analogue scale where 1 was marked “not at all” and 10 “very different”; 42%(24) scored 1, 14%(8) 2, 10.5%(6) scored 3, 7.0%(4) scored 4, 7.0%(4) scored 5, 5.3%(3) scored 6, 7%(4) scored 8, 5.3%(3) scored 9, and 1.7%(1) scored 10.

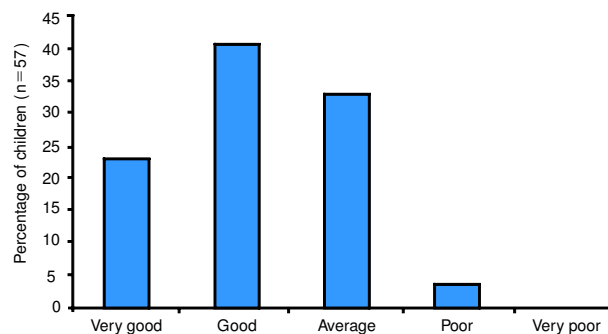
associated with the perception by the adolescents of their health. We have uncovered a number of aspects of the illness, nonetheless, that do not appear to be relevant to their perceived health, and some that do.

Discussion

The perception of their health by the adolescents appeared to be most closely related to their social world. Other important factors were the ability to make and keep friendships, or the degree to which they could keep up with their peers and participate

**Figure 3.**

Similarly, to the question "how serious do you think your condition is?" 7.0%(4) of the children replied 1 (not serious at all), 10.5%(6) replied 2, 12.3%(7) replied 3, 5.3%(3) replied 4, 24.6%(14) replied 5 (moderately serious), 10.5%(6) replied 6, 12.3%(7) replied 7, 12.3%(7) replied 8, 1.8%(1) replied 9 and 3.5%(2) replied 10 (very serious).

**Figure 4.**

Children were asked to rate their health on a five point scale. Of those questioned, 22.8%(13) endorsed "very good", 40.7%(23) "good", 33%(19) "average" and 3.5%(2) "poor". No child endorsed very poor.

Table 3. Statistical significance of the relationships of domain indexes with self-reported state of health and medically defined complexity of condition.

	Global health	Different from others	Seriousness of condition	Physician rated severity
Physical symptoms	0.0065	0.0011	0.5378	0.2003
Physical limitation (a)	0.0450	0.0798	0.1552	0.1302
Physical limitation (b)	0.0027	0.0040	0.6166	0.2694
Limitation of school PE	0.3156	0.0783	0.8285	0.6501
Social limitations	0.0095	0.0004	0.1628	0.0048
External pressure	0.1148	0.0079	0.7809	0.7164
General concerns	0.4332	0.0439	0.0045	0.7014
Physical concerns	0.0186	0.0010	0.2825	0.5607
Social concerns	0.0000	0.0003	0.6572	0.4424
Educational concerns	0.0125	0.0007	0.7764	0.3852
Total concern	0.0178	0.0008	0.1063	0.7996

Kruskal-Wallis test results corrected for ties. The numbers in the table represent the probabilities of *no* relationship between the variables

Table 4. Rank correlation coefficients of the relationships of domain indexes with self reported state of health and medically defined complexity of condition.

	Global health	Different from others	Seriousness of condition	Physician rated severity
Physical symptoms	0.4379**	0.6250**	0.2162	0.0561
Physical limitation (a)	0.2853*	0.4369**	0.4083**	0.1108
Physical limitation (b)	0.4468**	0.5941**	0.2655*	-0.0481
Limitation of school PE	0.0912	0.2978*	0.1304	-0.0402
Social limitations	0.4439**	0.5631**	0.1530	0.1001
External pressure	0.2871*	0.4594**	0.1366	-0.0723
General concerns	0.1500	0.3951**	0.6003**	0.0225
Physical concerns	0.4146**	0.6008**	0.3069*	0.0404
Social concerns	0.6306**	0.6911**	0.1889	-0.1269
Educational concerns	0.4374**	0.5019**	0.1581	-0.0493
Total concern	0.4200**	0.5830**	0.4966**	-0.0061

Spearman's rank correlation coefficients – **Significant at 1% level; *Significant at 5% level

in school activities. From the interviews, it became clear that many of the restrictions and social barriers were instituted by other people. In the view of the adolescents, these people usually underestimated the capacity of the adolescents to live a "normal" life. There is some objective evidence that may be the case. In a study of 26 children with surgically palliated complex cyanotic congenital heart disease, parents underestimated the exercise capacity of their children in four-fifths of cases.⁴ This suggests that it might be useful to give better guidance on levels of activity to those who interact with the adolescents, namely the parents, the teachers, and possibly also their peers. Of course, in some cases the adolescent may have overestimated his or her own abilities. Others may then have been justified in holding them back. Here again, health professionals might play a useful mediating role by proactively using objective exercise testing, and negotiating more objective limits with parents.

One of the most common ways in which the social relationships of these children were disrupted was by not being able to keep up with their peers in active pursuits, or by being marked out as different by obvious symptoms such as breathlessness or anoxia at relatively low levels of exertion. A number of studies of patients with congenital cardiac disease have investigated the effects of physical exercise training following surgery. Most have demonstrated reduction of symptoms and improvement in physical well being.¹⁹⁻²⁵ Larger and better-designed randomised controlled trials are required to determine the benefits of cardiac rehabilitation in this group.

The lack of relationship between the underlying complexity of the condition and the perception by the patients of the effect on their health remind us that it is not safe to assume that those with "simple" conditions will be in less need of psychosocial care and rehabilitation than those with complex medical problems. A similar lack of relationship between the extent of disability and the severity of the underlying cardiac condition is also found in adults with acquired cardiac illness.²⁶ This suggests that it will be important to develop tools reliably to assess the psychosocial, as well as the medical and functional, needs of these children when attending clinics.

Conclusion

The majority of the adolescents with congenital cardiac disease appear to regard their state of health as average or very good, and themselves as little different from their peers. Their self-reported burden of symptoms, and their perception of health, were most strongly related to the degree to which the condition disrupted their social relationships, and

not to the "complexity" of their defect as rated by their physicians. It may be that improving the understanding of those who are socially significant, and the stamina and functional ability of the adolescents through programmes of rehabilitation, will improve their quality of life.

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